

ORIGINAL

No Disc

REMARKS

BY

C. EVERETT KOOP, M.D.  
SURGEON GENERAL

OF THE

U. S. PUBLIC HEALTH SERVICE

PRESENTED TO THE

FIRST INTERNATIONAL CONFERENCE  
ON THE GLOBAL IMPACT OF AIDS

LONDON, ENGLAND  
MARCH 10, 1988

WE'VE HAD THREE DAYS TO LOOK AT ALL THE MYRIAD RAMIFICATIONS OF AIDS UPON THE HEALTH OF INDIVIDUALS -- AND OF SOCIETIES. I HAVE BEEN ASKED TO ADDRESS ONE OF THE NON-MEDICAL ISSUES: THAT IS, HOW DOES THE AIDS EPIDEMIC AFFECT THE BALANCE BETWEEN INDIVIDUAL FREEDOM AND THE PUBLIC INTEREST?

ONE OF THE EXTRAORDINARY ASPECTS OF THIS EPIDEMIC, BY THE WAY, IS THE VERY FACT SUCH AN ISSUE CAN BE RAISED AT ALL -- AND IT DOES NOT SEEM OUT OF PLACE.

WE TALK OF INDIVIDUAL FREEDOM -- OF PROFESSIONAL RESPONSIBILITY -- OF CIVIL RIGHTS AND WRONGS -- AND OF MANY OTHER ISSUES WHICH SEEM TO BE APPROPRIATE IN THE CONTEXT OF THE AIDS EPIDEMIC, BUT WHICH WOULD BE OF MARGINAL INTEREST -- OR OF NO INTEREST AT ALL -- IN THE CONTEXT OF ALMOST ANY OTHER INFECTIOUS DISEASE.

WITH THE POSSIBLE EXCEPTION OF LEPROSY. IN ANY EVENT, FOR THE NEXT FEW MINUTES I WOULD LIKE TO EXPLORE THIS ISSUE OF INDIVIDUAL FREEDOM AND THE PUBLIC INTEREST.

ONE WAY WOULD BE TO DO IT IN AN ABSTRACT PHILOSOPHICAL FASHION. FOR EXAMPLE, PEOPLE IN OUR SOCIETY ONCE GIVEN THE FACTS ARE ABLE TO MAKE A FREE CHOICE ON THE BASIS OF THOSE FACTS AND THEY INDIVIDUALLY AND COLLECTIVELY WILL BENEFIT.

THAT'S THE THEORY.

CONVERSELY, THE PERSON IN OUR SOCIETY WHO DOES NOT KNOW THE FACTS OF LIFE AND HEALTH -- FACTS THAT ARE KNOWN BY MOST OF HIS OR HER NEIGHBORS -- THAT IS NOT A FREE INDIVIDUAL, ABLE TO MAKE A CHOICE -- THAT'S NOT A THEORY, IT IS REALITY.

SUCH A PERSON -- IN THE REAL WORLD OF OUR INNER CITIES, FOR EXAMPLE -- MAY LACK INFORMATION ABOUT NUTRITION, ABOUT PERSONAL AND ENVIRONMENTAL SAFETY, AND ABOUT A GREAT MANY OTHER ASPECTS OF DAILY LIFE THAT SHAPE HIS OR HER DAY-TO-DAY EXISTENCE.

AND WE -- WHO NOW FEEL A COMPELLING NEED TO RELAY INFORMATION ABOUT AIDS TO HUNDREDS OF THOUSANDS OF SUCH INDIVIDUALS AT RISK FOR INFECTION -- WE MUST FACE THE POSSIBILITY THAT OUR MESSAGES TODAY ABOUT AIDS MAY BE AS UNSUCCESSFUL AS OUR MESSAGES YESTERDAY ABOUT DIET AND FAMILY PLANNING AND SMOKING AND FIRE PREVENTION AND SYPHILIS AND ALCOHOL ABUSE.

WE'VE TRIED TO DELIVER THE FACTS ABOUT THOSE AND MANY OTHER PUBLIC HEALTH MATTERS IN ORDER TO HELP OUR CITIZENS FREELY MAKE THEIR OWN CHOICES OF BEHAVIOR BASED ON GOOD INFORMATION -- IN OTHER WORDS, TO HELP THEM ACT AS FREE PEOPLE SHOULD ACT, FOR THEIR OWN BENEFIT AS WELL AS FOR THE BENEFIT OF THEIR COMMUNITY OR SOCIETY.

BUT -- FOR WHATEVER REASONS -- THEY HAVE NOT BEEN ABLE TO USE THE INFORMATION AND, THEREFORE, I WOULD SUBMIT THAT THEY ARE NOT FREE.

BUT I THINK YOU WOULD PREFER THAT I SPEAK TO THE SPECIFIC ISSUE OF HOW WE SERVE THE PUBLIC INTEREST AND PERMIT INDIVIDUAL FREEDOM WHICH IS THE HALLMARK OF OUR SOCIETY IN THE GLOBAL SENSE.

BEFORE ADDRESSING THE PROBLEM I MUST REMIND YOU THAT -- AT LEAST IN THE UNITED STATES -- EVERYTHING THAT IS THOUGHT, SAID, AND DONE ABOUT AIDS IS COLORED BY THREE FACTS:

- o IN SPITE OF ALL WE KNOW ABOUT AIDS, IT IS STILL SOMEWHAT OF A MYSTERY, ESPECIALLY TO NON-MEDICAL PEOPLE!
- o THE DISEASE IS VIRTUALLY 100% FATAL.

o PEOPLE GET AIDS BY DOING THINGS MOST PEOPLE DO NOT DO AND OF WHICH MOST PEOPLE DO NOT APPROVE.

THE REJECTION OF SUCH INDIVIDUALS COUPLED WITH THE FEAR AND MYSTERY OF AIDS INEVITABLY MEANS THAT THE DIAGNOSIS OF AIDS WILL BEAR A STIGMA.

THIS STIGMA -- AT LEAST IN THE U.S. -- HAS BEEN KNOWN TO DEPRIVE ONE OF HIS RENTED HOUSING, KEEP A FAMILY FROM GOING TO THE BARBER, SHOPPING AT THE SUPERMARKET, ATTENDING SCHOOL OR CHURCH.

SUCH OSTRACISM HAS LED TO A HEIGHTENED SUICIDE RATE AMONG PERSONS WITH AIDS AND, IN AT LEAST ONE INSTANCE, THE ARSON OF THE HOME OF THREE HIV POSITIVE CHILDREN WITH HEMOPHILIA.



SUCH UNFAIR AND UNJUST TREATMENT OF A FAMILY POINTS OUT THE WIDELY HELD PUBLIC HEALTH POSITION OF THE NEED FOR CONFIDENTIALITY WITH HIV TEST RESULTS AND WITH THE DIAGNOSIS OF PERSONS WITH AIDS.

CONFIDENTIALITY IS NOT IN CONFLICT WITH THE PURSUIT OF THE PUBLIC'S INTEREST IN THE LONG TERM. INDEED IT AUGMENTS IT BY NOT DRIVING THE AIDS PATIENT UNDERGROUND, BY PERMITTING HIS/HER TREATMENT OF OTHER STDs, BY WINNING CONFIDENCE, THUS ENABLING COUNSELLING OF THE INDIVIDUAL AND HIS/HER SEXUAL CONTACTS OR DRUG SHARING PARTNERS.

IN THE MATTER OF TESTING, I HAVE ARGUED AGAINST ANY KIND OF UNIVERSAL COMPULSORY TEST FOR AIDS. EVEN THE MOST GENEROUS ESTIMATE OF THE NUMBER OF PEOPLE WALKING AROUND WITH THE VIRUS TODAY -- AND IT'S CURRENTLY 1.5 MILLION AT THE OUTSIDE -- EVEN THAT ESTIMATE IS AN EXTREMELY SMALL FRACTION OF THE TOTAL U.S. POPULATION OF 240 MILLION.

AND, IN ANY CASE, WE ALREADY KNOW THAT 90 PERCENT OF ALL PERSONS WITH AIDS THUS FAR HAVE EITHER BEEN I.V. DRUG ABUSERS OR HOMOSEXUALS OR BISEXUAL MEN, AND THESE TWO GROUPS ARE THEMSELVES NOT LARGE.

IN ADDITION, THE OVERWHELMING MAJORITY OF HOMOSEXUALS AND BISEXUAL MEN HAVE BEEN UNTOUCHED BY THE EPIDEMIC. APPARENTLY ONLY A MINORITY OF THESE INDIVIDUALS HAVE ENGAGED IN THE KIND OF SPECIFIC HIGH-RISK BEHAVIOR THAT SPREADS THE VIRUS.

AND WE GATHER FROM SURVEYS DONE HERE AND THERE THAT THIS COMMUNITY OF MEN HAS UNDERGONE A VERY SERIOUS AND POSITIVE CHANGE IN BEHAVIOR. WE MIGHT EVEN EXPECT A DECLINE IN THE RATE OF AIDS REPORTING FROM THIS GROUP IN A YEAR OR SO.

IF IT SEEMED UNLIKELY BEFORE THE PUBLIC EDUCATION PROGRAMS THAT ALL HOMOSEXUALS WOULD BE STRICKEN WITH AIDS, IT SEEMS EVEN LESS SO TODAY.

THE I.V. DRUG ABUSER PRESENTS US WITH A DIFFERENT PROBLEM. THE PEOPLE OF THE UNITED STATES SEE THE DRUG HABIT ITSELF AS THE ISSUE. THE APPEARANCE OF AIDS WITHIN THE DRUG CULTURE IS JUST ANOTHER POTENTIAL CATASTROPHE FOR THE DRUG ADDICT -- ALONG WITH HEPATITIS, TUBERCULOSIS, DEMENTIA, STARVATION, SUICIDE, AND SO ON.

IT'S TRUE THAT MANY DRUG ADDICTS HAVE VOLUNTARILY PRESENTED THEMSELVES FOR AIDS TESTING -- BUT WE SUSPECT THAT THE MAJORITY OF THEM HAVE NOT -- AND WILL NOT.

OVER THE YEARS WE'VE BEEN SINGULARLY UNSUCCESSFUL IN PENETRATING THE DRUG-ADDICTED CULTURE WITH EVERY OTHER PUBLIC HEALTH MESSAGE WE'VE EVER HAD -- INCLUDING THE ONE THAT SAYS "STOP!"

IN ADDITION, THE SHEER VOLUME OF NON-AIDS DRUG-RELATED DEATHS -- THROUGH DRUG OVERDOSES OR DRUG-INDUCED VIOLENCE -- IS STILL VERY HIGH: ABOUT 5,000, ACCORDING TO THE F.B.I. AND OUR OWN NATIONAL INSTITUTE OF DRUG ABUSE. HENCE, THE HEART OF THE PROBLEM -- AND THE URGENT NEED FOR A SOLUTION -- IS THE ADDICTION ITSELF AND NOT THE SPECIFIC ACT OF NEEDLE-SHARING AMONG ADDICTS.

TESTING FOR HIV ANTIBODIES WILL NOT OF ITSELF CONTAIN THE EPIDEMIC. NOR WILL ANY OF THE MEASURES SOME ADVOCATES OF MANDATORY TESTING SUPPORT:

SUCH AS: QUARANTINE; USE OF IDENTITY CARDS; COMPULSORY CONTACT TRACING; PUBLIC RECORDING OF THE IDENTITY OF HIV POSITIVES.

NONE OF WHICH I SUPPORT.

MANDATORY TESTING HAS A PLACE WITH SOME GROUPS -- BUT NOT FOR THE MAJORITY. LET ME GIVE AN EXAMPLE OF ONE GROUP WHERE IT MAKES SENSE AND ANOTHER GROUP WHICH IT DOES NOT:

THE ARMED FORCES AND THOSE APPLYING FOR MARRIAGE LICENSES.

THE U.S. ARMED FORCES MANDATE TESTING OF ALL RECRUITS AND ACTIVE DUTY PERSONNEL -- FOR TWO REASONS:

FIRST, THEY ARE IMMUNIZED AGAINST EVERY DISEASE FOR WHICH THERE IS A DISEASE. A LIVE VIRUS VACCINATION COULD BE LETHAL TO HIV POSITIVE PERSONNEL.

SECONDLY, THE ARMED FORCES ARE THEIR OWN WALKING BLOOD BANK. THE LATTER REASON IS ALSO WHY OUR FOREIGN SERVICE PERSONNEL ARE TESTED.

PRE-MARITAL TESTING ON THE OTHER HAND IS EXPENSIVE AND WOULD NOT CONTAIN THE EPIDEMIC. THERE WAS A DAY WHEN A NEGATIVE PRE-MARTIAL TEST FOR SYPHILLIS WAS REQUIRED FOR A MARRIAGE LICENSE. HOWEVER, THERE WAS NOT ONLY A CURE FOR THE SYPHILLIS, BUT LIVING TOGETHER OUTSIDE THE BONDS OF MARRIAGE WAS FROWNED UPON. TODAY THAT IS NOT THE CASE. NOT ONLY IS THERE NO SUCH CURE FOR AIDS, BUT THE MAJORITY OF THOSE GETTING MARRIED HAVE ALREADY BEEN LIVING TOGETHER.

UNFORTUNATELY, THOSE WHO PRACTICE HIGH RISK BEHAVIOR, IN GENERAL, ARE NOT APPLYING FOR MARRIAGE LICENSES.



THE COMBINATION OF THE POSSIBILITY OF FALSE POSITIVES AND THE STIGMA ACCOMPANYING HIV POSITIVITY IS A RISK MANY YOUNG PEOPLE DO NOT WISH TO TAKE.

AND FINALLY THE COST BENEFIT RATIO IS VERY HIGH, BECAUSE ONLY A VERY SMALL NUMBER OF THOSE TESTED WOULD BE TRUE POSITIVES IN MOST COMMUNITIES. IN SOME STATES IT WOULD TAKE APPROXIMATELY \$100,000 TO FIND A SINGLE CASE.

ANOTHER AREA WHICH NEEDS MENTIONING IS THE FREEDOM OF THE PHYSICIAN, NURSE, DENTIST OR OTHER HEALTH CARE WORKER TO REFUSE TO TREAT PATIENTS WITH AIDS OR THOSE THEY MAY THINK MIGHT BE HIV POSITIVE. THIS FREEDOM IS CERTAINLY NOT IN THE PUBLIC INTEREST.

NEVER BEFORE HAVE HEALTH PROVIDERS IN THE U.S. TURNED DOWN A CLASS OF PATIENTS BECAUSE OF THEIR DIAGNOSES. WE NEVER DID IT FOR LEPROSY, YELLOW FEVER, SMALL POX, INFLUENZA, OR POLIO. AND WE MUST NOT DO IT FOR AIDS.

THERE ARE IN THE U.S. MORE THAN SEVEN MILLION HEALTH CARE WORKERS. FEWER THAN A DOZEN HAVE SERO-CONVERTED BECAUSE OF JOB RELATED ACTIVITY -- AND EIGHT OR NINE OF THEM WOULD NOT HAVE DONE SO IF THEY HAD FOLLOWED THE SIMPLE GUIDELINES SET DOWN BY THE CENTERS FOR DISEASE CONTROL SEVERAL YEARS AGO.

THE ISSUE OF TESTING PATIENTS IN HOSPITALS FOR HIV ANTIBODIES IS BEING MANAGED IN MANY PLACES ON A VOLUNTARY BASIS, WHICH THREATENS NO ONE'S INDIVIDUAL FREEDOM, YET DOES SEEM IN THE PUBLIC INTEREST.

VOLUNTARY TESTING WITH CONFIDENTIALITY IS BEING URGED IN MANY CIRCUMSTANCES, ONE MAJOR TARGET GROUP BEING COUPLES WHO CONTEMPLATE A PREGNANCY.

ONE CAN HOPE THAT AS WE BECOME MORE FAMILIAR WITH THE DISEASE OF AIDS, AND AS WE DROP THE MYTHS AND MISINFORMATION THAT THE STIGMA ASSOCIATED WITH THE DIAGNOSIS WILL DIMINISH AND THAT INFORMATION AND EDUCATION WILL ULTIMATELY CHANGE BEHAVIOR TO BRING ABOUT THE CONTAINMENT OF THE EPIDEMIC.

THE ECONOMIC, LEGAL AND ETHICAL IMPLICATIONS OF AIDS ARE ENORMOUS AND THREATEN THE SOCIAL COHESION OF WHOLE SOCIETIES. THE CHALLENGE TO MAINTAIN THE BALANCE BETWEEN INDIVIDUAL FREEDOM AND THE PUBLIC INTEREST IS ALSO ENORMOUS. IF WE CAN MANAGE IT IN FAIRNESS AND WITH UNDERSTANDING WE MAY GIVE THE WORLD SOMETHING AS PRECIOUS AS THE SCIENTIFIC BREAKTHROUGH WE ALL SEEK IN PREVENTION AND TREATMENT.